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Regaining Control

By Kristi Sweeney, CFP®

I could not shake the feeling. I had a constant chilling fear that I was having a stroke, suffering with cancer or dying of a heart attack. Every so often, I could feel a tingle in my skull, a knot in the back of my neck and my heart skip a beat. A check-up proved there was nothing physically wrong with me but I couldn't shake the concern. My doctor wasn't uneasy but my symptoms worried me.

These new physical sensations started soon after my husband had a major sudden stroke when he was a hardy 37 year old, at a time that he appeared to be in excellent health. Though in apparent good health myself, I felt certain something unexpected and catastrophic would happen to me, too. I had a disabled husband who couldn't read, write or talk and two suddenly bewildered children, ages 6 and 9, who had lots of years of growing up to do. If they couldn't have an intact father, they required an undamaged mother! Everyone in my family looked to me to hold their lives together and I was determined to do it. But would my health fail me? What would happen to my family if I became incapacitated or if I died?

Suffering from a condition that I now call "caregiver anxiety", my unease was caused by being too important in the lives of my loved ones. I knew no one could take my place.

I couldn't think of who would want to take my place! It was too much to handle. I paid household bills, managed financial accounts, drove my children's school carpools, made business phone calls, went to my husband's doctor's visits, completed claim forms, read plenty of books to understand the residuals of stroke, made the meals, did household chores, tried to make it up to my semi-orphaned children by having their friends to our house, going to the zoo, to movies, out to dinner and all manner of entertaining distractions.

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I also tried to find meaningful activities for my husband whose life had taken such an unexpected and unfortunate turn. I went with him when he attempted a few tries of volunteer work, I drove him to speech therapy, found an art teacher and drove him to classes. I researched enriched rehabilitation programs and medical therapies. I knew sometime soon I'd have to add in going to work (though he had some disability benefits that helped us through). I'd lost my life partner and gained a pretty demanding dependent. I'd lost a fun life as a young wife and took on a long term caregiver burden. My children needed me more because they lost the father they'd known and loved who now had a major disability that was not going to improve much and he could not take care of them anymore. What would my family do if I wasn't around?

Realizing that I had to take charge of the one aspect of my life that I could control, I knew I had to add another self-assignment to the inventory of my chores. This new task had to move to the top of my list. So I started to organize my affairs so my family could make it without me. It seemed impossible and overwhelming at the beginning because I knew so little about planning. Fortunately, the solutions were far simpler than I expected. Through careful and appropriate financial and estate planning, I eventually regained a normal sense of my own personal well-being.

With the help of my attorney, I set-up a testamentary trust, designated guardians for my young children, prepared power of attorney and living will documents, named a conservator and a guardian for my husband. Then, to protect my husband and children financially, I applied for insurance on myself. I purchased life and disability insurance (to protect the income I earned) and eventually long term care insurance (to protect assets if I were to become catastrophically disabled). This planning made me feel better. In fact, I thought this planning thing was such a great idea that by 1989, I had went back to work and became insurance licensed, selling health insurance, disability insurance (especially) and life insurance.

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Nine years later I went a little overboard with planning enthusiasm and started studying to learn all that I could about taxes, investing, wills and trusts. I loved all that I learned and was pretty convinced at the time that everyone should take this rigorous three year course with its requisite arduous hours of study if you want to successfully pass the final two day exam. I proudly became a Certified Financial Planner® about fifteen years after my husband's stroke.

Now I really had the knowledge it took to take command over my family's financial future. So, every few years I have updated our plan and I am in control –not of unexpected loss of health and disability, but assuring that my family will be well cared for. My knowledge has helped my clients as well and special needs planning has become the focus of my financial planning practice.

My husband still cannot talk, read or write very well, but, no matter, we have triumphed in every sense. He became an artist and creates beautiful bird, fish and turtle sculptures. He is extremely supportive and patient with the hours I have to spend away from him. We have raised phenomenally sensitive, strong, creative and loving children with zest for life and adventure. They are wonderful in part because of the stroke and the difficulties we faced and overcame together.

How do you cure “caregiver anxiety”? You do not have to become a Certified Financial Planner® practitioner like I did, but it sure helps to know one. Knowing that there are adequate financial resources and other people to care for your loved ones can give you peace and a sense of freedom and security. It will also provide you with a feeling of satisfaction that you have fulfilled perhaps the most important responsibility that you have as a caregiver: **Taking care of them when you aren't here anymore.**

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What kind of planning should you do? That depends entirely on your financial situation. However, preparation for the future can be done in one or more of these ways by anyone who is a caregiver:

1. Medicaid Planning- if you have modest income and assets, you can plan to avoid impoverishment if your disabled spouse may eventually need to go into a nursing home. Rules constantly change, so check with a knowledgeable elder care attorney.
2. Trusts- If properly set up, certain special trusts can allow your family member to be eligible for Medicaid benefits while also providing extra funds for special needs not covered by government benefits. This is a complex area that requires an attorney specializing in disability and elder care. A financial consultant familiar with this field can help you decide if you need to see an attorney for these types of trusts.
3. Estate Planning- will, trust, living will, medical and durable power of attorney are essential tools and can be set up for you by an attorney specializing in estate planning who is also familiar with disability considerations.
4. Beneficiary designations- Your largest assets may be your pension, life insurance policies and your home. These assets may pass to heirs outside of your will – and may have unintended consequences- unless special attention is paid to how these assets are titled or how beneficiaries are named. Get advice from financial planner specializing in disability planning.
5. Guardianships and Conservatorships- You can name a trusted person or persons who will take over responsibilities for financial and legal decisions for your disabled family member in case you are incapacitated.
6. Replacing your income and protecting your assets. You know how important you are to your family. Replacing what you do for your family would be expensive. If you are insurable, you can provide a great deal of security for both you and your disabled family member if you obtain life insurance, income protection and long term care insurance. Some long term care policies provide funds for both of you in your home if you, the caregiver, become disabled. A financial consultant specializing in disability and insurance planning can provide assistance in this area.
7. Letter of Intent- a loved ones severe cognitive disability or communication impairment may require that a caregiver pay special attention to preparing notes and care recommendations for a future caregiver. This can include, among many details, medical providers names and addresses, a

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description of your child's strengths and weaknesses and a list of activities of daily living preferences that will make your child's life as normal as possible.

Preparing for a secure future will relieve some of your caregiver anxiety. But remember that your plan is a work in progress. Monitoring you plan regularly with a financial advisor experienced in the special considerations of caregivers and their families will help you deal with inevitable life changes.

Kristi Sweeney, Certified Financial Planner™, has provided consultation services for twelve years. Her business, Sweeney & Associates, helps companies and individuals with benefit designs, disability claims assistance, long term care insurance and financial consultation for families with special needs. She served on the Rocky Mountain Stroke Association Board of Directors for five years from its founding in 1991. She resides with her family in Denver, Colorado.